



A Young Adult Discussion on Stigma Had By the Massachusetts DMH Statewide Youth Advisory Council

The Massachusetts Statewide Youth Advisory Council (SYAC) serves primarily as an advisory board to the Massachusetts Department of Mental Health, and was created to provide youth and young adult consumers in Massachusetts a voice in helping shape the mental health system for young adults. SYAC includes youth and young adults from across the state, some of whom are also members of their local area councils. In addition, SYAC reaches out to youth and young adult consumers, inviting them to its meetings and into its community to bring them hope and the possibility of recovery. SYAC has made a concerted effort to reduce stigma by providing real and candid presentations featuring youth who experience mental health challenges. We make this material available through various media including, but not limited to, a YouTube channel (www.youtube.com/user/voiceofSYAC), a website (www.transformation-center.org/communities/youth/index.html), and a SAMHSA/CMHR-sponsored documentary.

On September 16th, 2008, SYAC met at a local bookstore in Westborough, Massachusetts. Our main agen-

da item was to discuss the concept "stigma" in relation to our personal experiences. This article is a product of our discussion. I attended as council chair and coordinator, alongside about 20 additional members whose ages ranged from 16 to 29. Some of us worked in paid peer roles, while the rest either lived in the community or were residing in a nearby state hospital.

To start the conversation, I suggested that everyone speak generally about stigma. Some responses were that stigma manifests as a "judgment," a "label," a "biased prejudice." We all agreed stigma is "not always based on fact," or "not founded on any truth or on minimal truth." (But even when founded on minimal truth, stigma is a "stereotypical exaggeration.") By "pop-logic" processes stigma can cause personal shame in the stigmatized individual, and can also cause discrimination against the stigmatized individual or party. Our conclusion was that the main problem was: "You can be judged but the problem is you're being treated differently. More than being judged—being treated differently." As one member said: "My experience with stigma has been that

people expect less out of me because of my diagnosis. People think that I can't do things that 'normal' people can do such as work a full-time job or go to school because it is too much stress."

Some of the ways that stigma made us feel are "ashamed," "fear(ful)," and "helpless." We sense that other people "feel they may be better than [us]" when they stigmatize us. One council member said that because of his diagnosis and his experiences with his symptoms he felt "like an easy target." Other comments included, "The biggest problem with stigma: people don't listen to you. If you're being judged you don't get listened to," and the "little mistakes we make are considered [to be caused by] our mental illness. These are the same mistakes other people make too."

One young woman iterated what we all had felt at one time or another: that others believe that "just because she's in a mental hospital she must be crazy." She says that is "a miscommunication—just because we're in a hospital they think we're going to harm people. We're common people who just need a little more help. We can get jobs—do anything we want to.

Help is okay.” She said, “I’m okay the way I am.”

At one point the conversation became passionate; a true lash-back, illustrating our discontent with being so casually judged:

- “If they’re judging me, that’s their issue.”
- “Judging is a mental process. Everyone has a mental problem.”
- “I am trying not to get caught up in what other people think of me, just what I think of me.”
- “I know who I am and I am certainly not my diagnosis.”

Some of us decided it would be important to share how stigma has manifested itself in our lives:

- One member was “blamed for being in this place [a psychiatric hospital].”
- Another said, “Ever since I’ve been in the hospital, my stepmom won’t accept me for who I am. She won’t let me come home for visits with my dad. My siblings accept me but my stepmom can’t. The hospital said I can go home for visits. But my stepmom won’t allow me to live there. Actions speak louder than words: I’m getting better and working hard at getting better, but when I do she still takes the rug out from under me. People make you who you are—you’re made who you are.”



- Another member said he “didn’t feel like they [staff at hospital] paid attention to me until I started taking my meds.” He felt they were “covering up the problems.”

Other people in the group talked about their experiences with stigmatization:

- “One time I went to the hospital because I got an infection from a bee sting and I had to tell the nurse my diagnosis. Her immediate response was, ‘That’s a hard diagnosis, it must be hard.’ This woman doesn’t even know me and she is telling me that my life is hard. She heard my diagnosis, lumped me into a category and responded to that.”
- One participant was “denied informed consent in the past,” and did not always get “a say in what my diagnosis is.”
- “My entire junior high career I was called ‘freak’ and ‘crazy,’ because I was depressed and dressed differently, listened to different music. Sometimes large groups of kids would stare at me obnoxiously, walking down the halls. Sometimes kids would follow me around, making me anxious and making fun of me. Eventually the anxiety around school got so much that I couldn’t go and I was allowed to be home-schooled for the remainder of junior high.”
- A young woman from the group said she was “belittled by staff. The staff [at her treatment center] said they were in charge of my treatment, not me. They’re a bureaucracy. They hurt the people they’re trying to help. I haven’t done anything I used to do before at other programs. I say I don’t need to be there, but because of bureaucracy they have to keep me there for a certain amount of time.” As a group we all agreed that, generally, treatment is not individual enough.

Wisdom we wanted to pass on to individuals without any firsthand experience with a diagnosed individual was: Don’t judge others, because it’s just a reflection of yourself, not the

diagnosed individual. One member quoted Lewis Carroll: “We’re all mad here. I’m mad. You’re mad. We wouldn’t be here if we weren’t.”

At that point we went on a quoting spree of our favorite sayings, the two most relevant to this article being “rock bottom is good solid ground,” and “a dead end street is a good place to turn around.”

We do not feel less or worse because of our diagnosed experiences, but stronger of character and more open in general. We feel and hope for the same things everybody else does. “I try to live a life of meaning, purpose and fun,” said one council member. He also said, “the most valuable thing for me was to feel connected to other people.” Our pursuit of happiness is only deepened by our experiences with mental illness: “I needed a lot of self-care in those days and after I got back on my feet I started to want to get better and get healthier. This drive was strong in me and as the days went by it got stronger.”

As a group we agreed that stigma “needs to be eradicated!” We “need to educate on mental illness to help stop stigma.” Stigma does no one any good, but we feel that we cannot force anyone to cease perpetuating stigma. As a group, the most we can do is actively pursue an effort to present the truth about young persons with mental health conditions. It is ultimately up to those we educate to embrace this truth and increase their own awareness.

Authors

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The Massachusetts Statewide Youth Advisory Council is a group of transition age youth (TAY) consumers who come together to voice themselves in relation to issues pertaining to TAY consumers in Massachusetts, affiliated with both the Massachusetts Department of Mental Health and the Transformations Center.